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Implementation of the Renal NSF in the North East and Cumbria

Introduction

English Public Health Observatories have as one as their remits supporting the implementation of the National Service Frameworks (NSFs). This report provides a summary of a study that was set up in 2002 by the North East PHO to examine the implications of implementing the Renal NSF[1]. Part 1 of the Renal NSF was published in January 2004[1], but the remaining parts are still being developed.

It was anticipated that the North East & Cumbria would have well established and high quality renal services due to the work of an existing Regional Commissioning Group.

In the study, consideration was given to progress in developing Renal Services in the North East & Cumbria and likely implications for this area. This report identifies key issues which influence the quality of care in renal disease that are likely to have implications for NHS commissioning and service delivery. Findings are presented under the following headings:

- Data collection;
- Service planning and commissioning;
- Staffing;
- Care pathways;
- Patient access; and
- Transplantation.

The issues explored in this report are key aspects of service provision. A number of these areas are directly related to the standards published in Part 1 of the Renal NSF. Recommendations are mainly focussed on the region, but some are applicable at national level.

Contents

Summary of Recommendations

- All Renal Units should be required to return data to the UK Renal Registry and this needs to be properly funded;
- Strategic Health Authorities and PCTs in the North East & Cumbria need to ensure a longer term remit for the existing Regional Commissioning Group for renal services;
- Staffing levels should be reviewed including consultants, junior doctors, nurse roles and the use of technicians;
- Guidelines for screening and use of erythropoietin in primary care should be agreed and implemented. Referral guidelines should be developed taking into account the resulting impact on outpatient services;
- Pre-dialysis counselling should be provided by all Renal Units;
- Surgical links to renal medicine for vascular access should be clearly defined in all Renal Units;
- Access to renal replacement therapy and outpatient services should be improved in areas where access is currently poor;
- Renal Units should identify problems with existing patient transport providers and work with patients to improve the service.
- Access to and handling of donor organs needs to be improved;
- Access to theatres for transplant surgery could be improved but this should be balanced with access by other emergency services.

Study Method

This study was undertaken during 2003 before any parts of the Renal NSF were available. The study had two parts as follows:

- An examination of the availability, accuracy and completeness of data on renal disease; and
- A qualitative consideration of the views of commissioners and providers of renal services in the North East & Cumbria on the likely key aspects of service provision required for the implementation of the Renal NSF.

For the first part of the study, existence of the UK Renal Registry means that, with regard to renal replacement therapy (RRT) a comprehensive and standardised data set is already defined. Data from the UK Renal Registry is used in this report to illustrate the provision and quality of renal services in the North East & Cumbria. General issues of availability, accuracy and completeness of data are reported.

The second part of the study was undertaken in two stages. The first stage involved an examination of submissions to the Renal NSF process and discussions with three members of the Renal NSF External Reference Group to identify key issues of importance to the NSF. These issues formed the basis of the semi-structured interviews used in the second stage and undertaken by Meryl Deane with at least one clinician from each of the four Renal Units in the North East & Cumbria and at least one representative of the Regional Commissioning Group. Content analysis was used to interpret the interview findings and the common issues were further explored with reference to the literature.

This report presents the findings from both parts of the study and reports key findings and recommendations in relation to both data collection and provision and commissioning and provision of renal services in the North East & Cumbria.

Epidemiology of Renal Disease

What is renal disease?

Renal disease is disease of the kidney. Kidney function is essential for life. If the kidneys fail then the body is unable to excrete certain waste products, excess water and salts, and is unable to control the body's acidity leading to death.

Chronic renal failure (CRF) is a gradual and progressive loss of kidney function. End stage renal failure (ESRF) is an irreversible, long-term condition in which the kidneys fail and renal replacement therapy (RRT) – treatment to augment or replace the function of the failing kidneys – is required to maintain life.

Renal disease appears less common in the UK than in the USA, in 2001, for example:

- Prevalence was 566 per million population in the UK[2] compared to 1,403 per million population in the USA[3]; and
- Incidence rate was 93 per million population in the UK[2] compared to 336 per million population in the USA[3].

The acceptance rate onto renal replacement therapy (RRT) is a reflection of the incidence of end stage renal failure (ESRF). In the UK, this has risen from 20 per million population in 1980 to 101 per million population in 2002[4].

Prediction modelling by the UK Renal Registry suggests an increase in the numbers of patients on RRT for the next 20 years - probably to an annual incidence of about 100-110 per million population - when the numbers should stabilise. Prevalence will therefore also increase.

Factors affecting the level of renal disease level in a population

The level of renal disease in a population is influenced by a number of key factors in the population. The incidence of renal disease is higher in those of a South Asian and African Caribbean descent. Patients with high blood pressure and diabetes, which is increasing, also have a higher incidence of renal disease. Patients who have had renal disease in the past are at higher risk of developing renal failure. The incidence of renal disease rises with increasing age, the incidence is thus higher in older populations.

Population levels of renal disease appear lower in Europe than in the USA[5,6,7,8] with the UK having a lower treatment rate than much of the rest of Europe. The length of time of progression of chronic renal failure to end stage renal failure (ESRF) is very variable. Early intervention may slow or halt the progression of chronic renal failure (CRF)[9,10]. Key factors leading to the development of chronic renal failure (see Table 1) are:

- Diabetic nephropathy;
- Hypertensive vascular disease; and
- Glomerular disorders.

Regular assessment of at risk patients is important. Persistent high blood pressure and heavy proteinuria are strong predictors of progression of chronic renal failure. The use of good control of blood pressure lowering, good diabetes management, ACE inhibition and the avoidance of nephrotoxins may slow the decline of renal function[11].

Table 1: Causes of End Stage Renal Failure (ESRF) for new adult patients 2002 for England & Wales[4]

Cause of End Stage Renal Failure	% of new patients aged	
	< 65	65 &+
Uncertain aetiology (Glomerulonephritis unproven)	17.5%	26.5%
Glomerulonephritis	13.5%	6.5%
Pyelonephritis	6.7%	6.3%
Diabetes	20.4%	14.5%
Renal vascular disease	2.8%	11.2%
Hypertension	5.1%	5.9%
Polycystic kidney	9.9%	3.0%
Other	14.4%	12.6%
Not recorded	9.6%	13.6%

Source: UK Renal Registry, 2003.

Ethnicity

Renal disease is more common in people of Asian and African Caribbean decent with acceptance rates to renal replacement therapy which are four times higher than in Caucasians[12,13].

Age and sex

There is a steep rise in acceptance on to renal replacement therapy with age[12]. Much of the increase in RRT over the last 20 years is due to the increased use of RRT in the over 65 population[14,15]. The increase in age of patients will lead to an associated increase in co-morbidity. Incidence of RRT is higher in men compared to women, with a ratio of about 1.5:1[2].

Deprivation

Incidence of RRT appears higher in more deprived areas (using Townsend score)[4]. In part, this may be due to patients on RRT from ethnic minorities being from more deprived areas. Patients from the

deprived areas are younger, have more co-morbid conditions, and have poorer 1 year survival which can be explained by cardiovascular co-morbidity.

Renal service commissioning

Services for renal disease are one of the agreed national specialised services and are therefore subject to special commissioning arrangements. In the North East & Cumbria, commissioning for renal services is undertaken by a Regional Commissioning Group and takes into account the national definition of renal specialised services[16]. All nephrology including end stage renal failure (ESRF), acute renal failure (ARF), general nephrology and renal related surgery should be included.

Options for treatment

There are three main types of renal replacement therapy (RRT) for the treatment of end stage renal failure (ESRF). These are:

- Transplantation;
- Haemodialysis; and
- Peritoneal dialysis.

Transplantation

The preferred option for the majority of patients is transplantation, which when successful provides a good quality of life without the need for dialysis. Organ donation is from two principle sources, live related donors and donations from people who have died. The majority of the cadaver donations are from heart beating donors where there is brain stem death. More recently a non heart beating donor programme has been developed; in these cases the kidneys have to be retrieved and transplanted within 24 hours. There is a shortage of organs for transplantation. Transplantation is likely to be less suitable for patients with significant co-morbidity, and with a likely increase in co-morbidity may be unsuitable in a higher proportion of patients in future years.

Haemodialysis

Haemodialysis involves removing toxic products by attachment of dialysis equipment to the blood circulation of the patient and dialysing the blood. Current good practice is to offer haemodialysis three times a week. The process takes several hours, and is based in general in haemodialysis units. A small number of patients have home haemodialysis machines.

Peritoneal dialysis

Peritoneal dialysis can be undertaken at home and is preferred by some patients. Patients do require some residual renal function for peritoneal dialysis. With an increasing proportion of elderly patients and patients with co-morbidity likely in future, a lesser proportion may be suitable for peritoneal dialysis. Continuous ambulatory peritoneal dialysis is now being replaced with automated peritoneal dialysis, which may be undertaken overnight.

While an increasing elderly and co-morbid population will increase the overall demand for RRT, the increased incidence of co-morbidity is likely to increase the proportion of haemodialysis required.

Erythropoietin

Erythropoietin is used in ESRF to treat anaemia. It is administered either subcutaneously or intravenously. It is used both while on dialysis and pre-dialysis. It is expensive.

Services in the North East & Cumbria for renal disease

There are four Renal Units in the North East & Cumbria as follows: Newcastle, Middlesbrough, Sunderland, and Carlisle. Each unit also has one or more satellites working in association with the unit.

Table 2: Renal Units and their satellites serving the North East & Cumbria, 2004

Renal Unit	Unit Hospital	Satellite(s)
Newcastle	Freeman Hospital	Royal Victoria Infirmary *A satellite is planned for Wansbeck General Hospital*
Sunderland	Sunderland Royal Hospital	University Hospital of North Durham
Middlesbrough	James Cook University Hospital	Darlington Memorial Hospital North Tees University Hospital
Carlisle	Cumberland Infirmary	Cockermouth Hospital

Source: Renal Units in the North East & Cumbria, 2004.

Satellite units also undertake haemodialysis, but patients who are unwell are dialysed at the main unit in each case. Satellite units are fully staffed with haemodialysis staff but in general, have no on site specialist renal physicians.

Table 3: Prevalent cases of Renal Replacement Therapy (RRT) in Renal Units in the North East & Cumbria, 31st December 2002[4]

Renal Unit	Estimated Catchment Population (millions)	Number of patients		
		Dialysis	Transplant	Total RRT
Newcastle	1.31	189	465	654
Sunderland	0.34	127	129	256
Middlesbrough	1.00	242	280	522
Carlisle	0.36	85	85	170

Source: UK Renal Registry, 2003.

Table 4: New adult patients accepted onto Renal Replacement Therapy, 2002 for Renal Units in the North East & Cumbria[4]

Renal Unit	Estimated Catchment Population (millions)	Number of Patients	Rate per million
Newcastle	1.31	105	80
Sunderland	0.34	56	165
Middlesbrough	1.00	112	112
Carlisle	0.36	29	81

Source: UK Renal Registry, 2003.

Data on renal disease

The UK Renal Registry

The UK Renal Registry is registered as a charitable activity. It was initially set up by the Renal Association, with support from the Department of Health, the British Association of Paediatric Nephrologists and the British Transplant Society. It is now funded primarily by individual Renal Units who pay an annual fee of £12 per patient for registration. The Registry reports that this method of funding enables them to maintain a level of independence[17].

The UK Renal Registry provides the collection and analysis of standardised data on the incidence, clinical management and outcomes of renal disease and acts as a source of comparative data, for audit, benchmarking, planning, clinical governance and research. Data are collected quarterly by automatic downloading from Renal Unit databases.

Current functions of the UK Renal Registry are to:

- Collect demographic and descriptive data for comparison and planning;
- Facilitate comparative audit by means of a carefully defined data set;
- Collect data on indicators of quality of care to facilitate audit against recommended national standards, improved care, and identification of good practice;
- Produce national and local outcome data; and
- Publish Annual Reports to allow comparative audit of facilities, patient demographics, quality of care and outcome measures.

At present, the data concentrates on renal replacement therapy, including transplantation. At a later date the data will include other forms of treatment of renal disease.

The UK Renal Registry, where possible, is starting to provide population data on incidence and prevalence. This is currently being produced at former Health Authority level. As the service is being commissioned as a specialised service, data are not required at individual PCT level.

Not all Renal Units are as yet returning data to the UK Renal Registry. At the end of 2002, about 80% of the UK was covered by the Registry and by the end of 2003, 90% coverage will have been achieved; all remaining Renal Units in the UK were considering participation in the Registry[18]. Until such time as all units are actively participating in the UK Renal Registry, gaps will remain in the data. However, the Renal Registry is a valuable source of data to support the commissioning of renal services; its value will increase as its coverage improves.

The UK Renal Registry provides data for participating Renal Units, NHS Trusts, and commissioners of care. The development of the Registry is open to influence by all interested parties including clinicians, trusts, commissioning authorities, and patient organisations.

UK Renal Registry data in the North East & Cumbria

The following Centres have for some time been participating in the UK Renal Registry: Middlesbrough (James Cook University Hospital), Sunderland (Sunderland Royal Hospital), and Carlisle (Cumberland Infirmary).

Newcastle (Freeman Hospital) joined the UK Renal Registry in 2001. Initially there were problems with data quality and validity in Newcastle, but these have now been resolved. Data for 2001 were found to be of insufficient quality to be included in the UK Renal Registry's 2002 report[2]; data for 2002 were of the quality required for inclusion in the 2003 report[4].

Tables 5-9 provide a summary of data for the North East & Cumbria provided by the UK Renal Registry.

Table 5: Prevalence of Renal Replacement Therapy (RRT), 1998-2002 by former Health Authority areas in the North East & Cumbria [4]

Former Health Authority area	Prevalence (Rate per million population)				
	1998	1999	2000	2001	2002
Northumberland	n/a	n/a	n/a	207	604
Newcastle & North Tyneside	n/a	n/a	n/a	232	574
Gateshead & South Tyneside	n/a	n/a	n/a	280	600
Sunderland	431	438	452	489	558
County Durham & Darlington	336	344	393	466	579
Tees	466	482	518	546	561
North Cumbria	485	501	504	542	526

Source: Renal Registry, 2003.

Low prevalence for County Durham & Darlington and Sunderland Health Authorities before 2002 reflects the lack of data from Newcastle which serves some parts of County Durham and Sunderland. Problems with data quality from the Newcastle Renal Unit resulted in severe undercounting for 2001 which have since been resolved[4]; it will be interesting to see if prevalence figures for Northumberland, Newcastle & North Tyneside, and Gateshead & South Tyneside increase further when figures for 2003 are released.

Table 6: Prevalence of Renal Replacement Therapy (RRT), 31st December 2002 by former Health Authority areas in the North East & Cumbria [4]

Former Health Authority area		Dialysis		Transplant		All RRT	
	Total pop.	Number	Rate per million	Number	Rate per million	Number	Rate per million
Northumberland	309,600	74	239	113	365	187	604
Newcastle & North Tyneside	470,100	102	217	168	357	270	574
Gateshead & South Tyneside	353,500	84	238	128	362	212	600
Sunderland	292,300	61	209	102	349	163	558
County Durham & Darlington	607,800	154	253	198	326	352	579
Tees	556,300	131	235	181	325	312	561
North Cumbria	319,300	79	247	89	279	168	526

Source: Renal Registry, 2003.

Prevalence of RRT varied between 342 and 930 per million population in England and Wales in 2002; the estimated England average was 615 per million population and the estimated UK average was 626 per million population[4].

Table 7: Incidence of Renal Replacement Therapy (Acceptance rate onto RRT) in adults, 1998-2002 by former Health Authority areas in the North East & Cumbria [4]

Former Health Authority area	Incidence (Acceptance rate per million population)				
	1998	1999	2000	2001	2002
Northumberland	n/a	n/a	n/a	n/a	77.5
Newcastle & North Tyneside	n/a	n/a	n/a	n/a	89.3
Gateshead & South Tyneside	n/a	n/a	n/a	n/a	101.8
Sunderland	51.3	85.5	82.1	88.9	95.8
County Durham & Darlington	100.4	74.0	72.4	75.7	98.7
Tees	107.9	91.7	82.7	93.5	116.8
North Cumbria	125.3	72.0	68.9	78.3	94.0

Source: Renal Registry, 2003.

Low incidence rates for County Durham & Darlington and Sunderland Health Authorities before 2002 reflect the lack of data from Newcastle which serves some parts of County Durham and Sunderland. Additionally, it will be interesting to see if incidence figures for Northumberland, Newcastle & North Tyneside, and Gateshead & South Tyneside increase when figures for 2003 are released.

The rate of acceptance on to treatment in end stage renal failure (ESRF) in the UK has been less than in Europe for some years. The level of treatment for ESRF in the UK has increased in recent years[14,18]. The number of renal units has remained fairly constant; the increase has been enabled through an increase in number of haemodialysis stations, an increase in the number of shifts, and the development of satellite units[18]. The rate of acceptance (incidence) may have stabilised, but the prevalence is increasing as survival on RRT increases.

Table 8: Incidence of Renal Replacement Therapy (Acceptance rate onto RRT) in adults, 2002 by former Health Authority areas in the North East & Cumbria[4]

Former Health Authority area	Population	Number of Patients	Rate per million
Northumberland	309,600	24	77.5
Newcastle & North Tyneside	470,100	42	89.3
Gateshead & South Tyneside	353,500	36	101.8
Sunderland	292,300	28	95.8
County Durham & Darlington	607,800	60	98.7
Tees	556,300	65	116.8
North Cumbria	319,300	30	94.0

Source: Renal Registry, 2003.

The estimated England average incidence was 98 per million population and the estimated UK average incidence was 101 per million population[4]. Incidence rates of RRT for adults varied between 58.0 and 175.4 per million population in 2002 for former English health authority areas.

Table 9: Unadjusted survival at 1 year of new patients with end stage renal failure (ESRF), 2001 cohort for England & Wales[4]

Age Group	% survival at 1 year
18-34	97%
35-44	95%
45-54	91%
55-64	80%
65-74	70%
75-84	66%
85+	49%

Source: Renal Registry, 2003.

One year survival with ESRF, predictably, demonstrates a decline with increasing age.

Study Findings

The study identified 6 issues which are likely to be key to the implementation of the full Renal NSF. These were as follows:

1. Data collection.
2. Service planning and commissioning:
   - Predicting future need;
   - Specialised commissioning;
   - Taking account of population factors;

3. Staffing:
   - Consultant staffing;
   - Staffing of haemodialysis;
   - Staff mix.
4. Care pathways:
   - Screening in primary care;
   - Guidance on referral from primary care;
   - Erythropoietin pre-dialysis;
   - Pre-dialysis counselling;
   - Vascular access.
5. Patient access:
   - To renal replacement therapy;
   - To outpatient facilities;
   - During holidays;
   - Patient transport.
6. Transplantation:
   - Equity;
   - Ethnicity;
   - Donor organs;
   - Time from harvest to transplant;
   - Theatre access.

These issues are discussed in more detail below.

1. Data collection

Adequate data should be returned to the UK Renal Registry. Data collection needs to be sufficiently funded.

Data collection across the North East & Cumbria concerning patients with end stage renal failure (ESRF) is now standardised to collect the data set required by the UK Renal Registry. This includes basic demographic data together with a comprehensive data set covering type of treatment, biochemical parameters relating to treatment, and co-morbidity. This data set is extremely comprehensive and included data items are well defined, although in this study some anxiety about definitions of co-morbidity was expressed by clinicians.

Data collection is funded by the Renal Units paying a registration fee for each patient. Comprehensive analyses are produced by the UK Renal Registry on an annual basis. This report includes epidemiological data such as the uptake of RRT as well as information on quality indicators.

Data collection in Renal Units has developed in an ad hoc manner and funding for this is often not clearly identified. Units varied in their use of audit or review of data to assess their service provision.

2. Service Planning and Commissioning

Future prediction of need

Provision of renal replacement therapy (RRT) was felt to be reasonable, with a view that the North East & Cumbria had historically been fairly well provided for. It was generally thought that the incidence of end stage renal failure was either plateauing or continuing to increase, but was not declining. Local and national data supported this view. Even where the number of new cases was not thought to be increasing, improved survival means that the prevalence of RRT is increasing.

The UK acceptance rate onto renal replacement therapy (RRT) was 20 per million population in 1980 rising to 101 per million population in 2001[4]. Prediction modelling undertaken by the UK Renal Registry suggests an increase in the numbers of patients on RRT for the next 20 years, when the numbers should stabilise[19].

Specialised commissioning

The service should be commissioned as a specialised service on a 'regional' basis. PCTs will need to ensure they are able to implement the Regional Commissioning Group's recommendations.

There is a Regional Commissioning Group for renal services in the North East & Cumbria. This includes Trust clinicians and managers together with commissioners. Overall, clinicians felt that this was an effective group. However, the group does have a limited role, with little (or no) consideration of primary care issues. The group was also formed for a defined period of time, this being for about 1 further year.

Population factors

The known ageing population is responsible for most of the increase in uptake in RRT. Adequate access to renal expertise for this cohort of patients is required. Patients could be referred to renal medicine or to physicians for the elderly.

Levels of renal disease are higher in people of Asians and African Caribbean decent. This has a considerable effect on the level of RRT required in areas with a high density of these populations.

Clinicians had mixed views about the most appropriate route of referral for elderly patients with renal disease. Options include only using renal physicians or some referral to elderly medicine. In general it was felt important that such patients had access to a specialist although this could be to a geriatrician or physician with an interest in renal medicine. Clear links between such services would need to be in place.

There is a predominantly Caucasian population in the North East & Cumbria, but there are major issues elsewhere in the country with an increased requirement for RRT in African Caribbean and Asian populations.

Increasing incidence of diabetes in the population will inevitably lead to an increased requirement of RRT.

3. Staffing

Consultant staffing levels

The balance of the number of renal consultants and associated junior staff compared to patient population is important in ensure an appropriate service is in place.

Table 10: Consultant staffing levels at Renal Units in the North East & Cumbria, 31/01/04

	Newcastle	Middlesbrough	Sunderland	Carlisle
Number of Consultants	5	5	4	2
Whole time equivalents	4	4	3.5	1

Source: Renal Units in the North East & Cumbria, 2004.

Consultant numbers only are shown, due to the complexities of junior medical staff numbers. Workload varied dramatically between Renal Units. This was influenced considerably by varying general medicine workloads; this had quite an impact on 'actual' nephrology time. All consultants were experiencing some

difficulties with workload. Interview findings were a view that Newcastle has poor consultant staffing levels, while Middlesbrough has difficulty sustaining the wide network of outpatient clinics it runs.

Despite providing a service to a larger population, Newcastle had the same consultant establishment as Middlesbrough. This was however substantially compensated for by Newcastle's much higher level of middle grade cover. Middlesbrough appeared to be especially short of middle grade cover.

Availability of trained staff to run haemodialysis service

Historically haemodialysis units have been fully staffed by nurses. In more recent times some services have utilised technicians to provide some dialysis care.

No local problems with recruitment were reported, although staff retention was sometimes problematic.

Staff mix

Newcastle, Middlesbrough and Carlisle use nurses to staff their haemodialysis units, with some nurse assistant support. Sunderland makes a greater use of technicians, with a nurse to technician ratio of 60:40. Nurses have a wider range of skills, being able to plan and evaluate care as well as deliver care; technicians only deliver care. All the units had developed nurse practitioners or nurse specialists in some areas, but these varied widely. Examples included nurse practitioners in a clinical investigations unit, a transplant facilitator, pre-dialysis nurses, and an anaemia co-ordinator. Most interesting was the use of a Nurse Consultant in the Durham satellite unit.

4. Care pathways

Screening in primary care

Appropriate screening in primary care will improve early diagnosis of chronic renal failure.

Patients at high risk of developing renal problems are those with a history of renal disease and those with diabetes. At increased but lesser risk are those with hypertension and those with CHD. These cohorts of patients should have blood urea and electrolytes undertaken at diagnosis and thereafter probably on an annual basis. The use of urine testing for protein in this group is also important.

Primary care referral guidance

Guidelines should be in place to ensure appropriate patients are referred early to renal medicine.

Consultants felt that early diagnosis was important and that they were able to reduce progression to end stage renal failure. However, there is very little existing guidance about referral from primary care; most notably when to refer patients was not the subject of guidelines.

Overall consultants felt that referral of patients with a creatinine of 150 µmol/l or higher should be referred for a renal opinion, but were concerned about the numbers this would generate and their capacity to meet demand in such cases. They had not considered how such an increase in demand might be met. It was unclear whether all patients with a high creatinine needed to be seen by a renal physician in out-patients or whether a letter based opinion or alternative service could suffice in some cases.

Erythropoietin pre-dialysis

Shared care protocols should be in place concerning the use of erythropoietin in primary care.

Access to erythropoietin pre-dialysis is an important component of modern renal medicine. Erythropoietin is administered either subcutaneously or intravenously. If erythropoietin is not available to the patient in primary care, or the patient is unable to self administer, they may have to travel to the Renal Unit for injections.

Shared care protocols between GPs and Consultants were in place in Newcastle, Sunderland and Carlisle, but not in Middlesbrough. It is, however, unclear if shared care protocols had been adopted by every related PCT. Some localised problems were reported. Some consultant nephrologists perceived that the major barrier to the implementation of shared care protocols was funding. There did appear to be issues with funding for erythropoietin being allocated to Trusts leading to perceived difficulties transferring care, where appropriate, to primary care. With PCTs such barriers in theory ought to be more easily overcome, but historic patterns of care may confound this.

Pre-dialysis counselling

Pre-dialysis counselling (where appropriate), is important to ensure patients are able to make an informed choice between modes of dialysis.

Newcastle, Middlesbrough and Carlisle Renal Units are able to offer pre-dialysis counselling. Sunderland Renal Unit cannot offer formal counselling, but patients are seen by a nurse pre-dialysis.

Vascular access

Vascular access is required for haemodialysis. An arteriovenous fistula is normally used. If there are delays in providing proper vascular access patients may have to be dialysed through temporary neck lines. This carries infection (and other) risks.

The availability of adequate vascular access is dependant on surgeon time and theatre time. Vascular access surgery can in general be undertaken under regional anaesthetic; more complex cases require general anaesthetic. Neck lines are often inserted in the radiology department and this can be quite a significant workload. The accessibility of provision of vascular access varies greatly between Renal Units.

Newcastle

Vascular access is undertaken by the transplant surgeons who hold weekly vascular access clinic. The service is currently provided by a single surgeon, although there is funding for a further surgeon to undertake some of the procedures. The waiting time is short – about 3 weeks. Although there are three lists a week there are constraints on theatre time, and available time is insufficient. Funding is available to improve the local service (possibly using a staff grade doctor). There is no dedicated radiology input in outpatients, and poor access to radiology services. It was felt that this was primarily due to inadequate numbers of radiology staff. In addition it was felt that links to radiology could be improved.

Sunderland

A hospital practitioner does one list a week of fistulas. Complex cases are referred on to the vascular surgeons. A weekly clinic is held by a vascular surgeon. Patients will usually be operated on within the same week, complex cases are done under general anaesthetic in main theatres.

Middlesbrough

Vascular access is undertaken by vascular surgeons. Access is generally good with a waiting time of 2-3 weeks. However, there was not a dedicated service and it was felt a dedicated link to vascular surgery would help improve the service.

Carlisle

The vascular surgeons have recently taken on this work. There is no dedicated time for this service but there are 2 vascular surgeons involved. No problems were reported with the service apart from a lack of beds.

5. Patient access

Access to renal replacement therapy

The provision of renal replacement therapy (RRT) should be adequate to allow patients to access haemodialysis locally. Haemodialysis should be offered to patients three times a week. This has clear implication for patients travelling between home and the unit, and therefore there should be spare capacity so that patients can be offered the choice of unit.

Table 11: Numbers of patients with ESRF on treatment at 31/01/04 by Unit and satellite

Renal Unit and Satellite(s)	**No of haemodialysis stations**	**No of haemodialysis slots**	**No of patients on haemo-dialysis**	**No of patients on peritoneal dialysis***	**No of transplanted patients***
Newcastle Renal Unit					
Freeman	19	134	134	42	549
RVI	17	83	70		
Sunderland Renal Unit					
Sunderland	20	120	83	17	143
Durham	12	48	29		
Middlesbrough Renal Unit					
Middlesbrough	20 + 8 temp	152	149	22	312
Darlington	13	74	74		
Stockton	0	0	0		
Home	3	3	3		
Carlisle Renal Unit					
Carlisle	14	56	62	19	85
Cockermouth	3	12	12		

Source: Renal Units in the North East & Cumbria, 2004

Note: * figures presented are for the whole Renal Unit including satellites.

All of the Renal Units in the North East & Cumbria work a 6 day week allowing cleaning time on the 7th day. Three shifts a day is usual in Renal Units with two shifts in satellites. Newcastle (Freeman) however, has 4 shifts a day with one late evening shift finishing about 2:00 a.m. There was limited spare capacity at the time of the study.

There is little or no spare capacity in Newcastle. There is a shortage of space at present. The Newcastle Renal Unit is planning developments including new and expanded facilities at the Freeman Hospital (due in 2005). The satellite unit at the Royal Victoria Infirmary will then close.

There is no haemodialysis provision in Northumberland. This is currently being reviewed and a satellite unit in Ashington (at Wansbeck General Hospital) is proposed. There is some spare capacity in Sunderland, Middlesbrough and Carlisle.

Access to outpatient facilities

Patients should have access to outpatients locally, where possible.

Table 12: Location of outpatient facilities

Renal Unit	Outpatients held in:
Newcastle	Newcastle (Freeman Hospital)
	Newcastle (Royal Victoria Infirmary)
	Gateshead (Queen Elizabeth Hospital)
Middlesbrough	Middlesbrough (James Cook University Hospital)
	Stockton (North Tees University Hospital)
	Northallerton (Friarage Hospital)
	Hartlepool (Hartlepool University Hospital)
	Darlington (Darlington Memorial Hospital)
	Bishop Auckland (Bishop Auckland General Hospital)
Sunderland	Sunderland (Sunderland Royal Hospital)
	Durham (University Hospital of North Durham)
Carlisle	Carlisle (Cumberland Royal infirmary)
	Whitehaven (West Cumbria Hospital)

Source: Renal Units in the North East & Cumbria, 2004

The Middlesbrough Renal Unit has made considerable efforts to ensure local outpatients are provided in all surrounding District General Hospitals. Outpatient access in Northumberland, North Tyneside, and South Tyneside is to hospitals in Newcastle, Gateshead and Sunderland.

Holiday access

Ideally all units should be able to accommodate patients from other areas of the country while on holiday in the area.

Most of the Renal Units in the North East & Cumbria are able to offer holiday haemodialysis but this does depend on availability.

Transport

Patients attend for haemodialysis three times a week. Transport needs to be as accessible and efficient as possible with minimum possible waiting times.

Delays were felt to be responsible for quite a lot of patient distress. All units felt that some aspects of the transport service could be improved. Inflexible contracts with ambulance services mean that patients are sometimes disadvantaged.

Newcastle

Transport is provided by the ambulance service and some long delays were experienced.

Sunderland

Transport was predominantly a car-based service, which was felt to work well. Where an ambulance-based service was used, waits could be long. Difficulties were experienced with transport to outpatients and the rigid schedule of the ambulance service.

Middlesbrough

An ambulance-based service is used. The transport in Middlesbrough was reported as being poor. There were particular problems with the timing of ambulances for outpatients.

Carlisle

Transport is provided by a car-based service; waits were felt to be reasonable. No problems were experienced with early or late haemodialysis sessions.

6. Transplantation

There is a need to ensure equity of availability of transplantation. Key factors influencing this are ethnicity, age and distance from transplantation centre.

There is a shortage of organs and surgeons. There is a particular shortage nationally of organs from non-Caucasian donors.

The North East & Cumbria has a single service for transplantation based in Newcastle which also undertakes liver transplants. The transplant co-ordinators are based in Newcastle. It is hoped to employ a further transplant co-ordinator based in Sunderland. There is a live donor co-ordinator based in Middlesbrough.

Equity

Clinicians from all the Renal Units felt they were being offered an equitable service from the transplant unit, this is confirmed by figures from the UK Renal Registry[4].

Ethnicity

The North East & Cumbria has a predominantly Caucasian population.

Donor organs

There is a national shortage of donor organs.

Cadaver organs

The numbers of cadaver organs becoming available has been falling. The average wait for a transplant in Newcastle is 388 days but the range is very wide. Newcastle has the lowest average wait in the country, the national average being 642 days (range 388-1,282 days).

The non-heartbeating donor programme has run in Newcastle from 1998. At present there are a number of other units in the UK implementing a similar service following promotion by UK Transplant. The non-heartbeating donor removals are undertaken by a single consultant surgeon. These kidneys should have a cold ischemic time of 24 hours or less. UK Transplant has increased the funding in order to increase number of junior surgeons in Newcastle; this will increase the availability of surgeons to do retrievals.

Live donors

Newcastle uses two theatres when undertaking live transplants; this requires additional theatre space but this is thought to improve results for both donor and recipient. The cold ischemic time is reduced by parallel, rather than sequential, operating. Newcastle has a capacity to undertake 20 live related transplants a year. They undertake the donor procedure laparoscopically where possible. Newcastle is one of only three Units offering laparoscopic surgery at present and, in consequence, is getting some national referrals.

Newcastle is a combined liver & kidney transplant unit. Liver transplants often take priority over live kidney transplants which means that a kidney transplant may be delayed, increasing the cold ischemic time.

Time from harvest to transplant (cold ischemic time)

The lower the cold ischemic time, the better the transplant survival. Newcastle has a median cold ischemic time of 21 hours. The national average is 19 hours. The Newcastle service takes a longer time to book kidneys in. Additionally, access to emergency theatres was also not ideal, both contributing to the length of cold ischemic time.

Theatre access

There is no dedicated emergency theatre for transplants - so kidney transplants have to fit in with other emergencies. Dedicated theatre time would however have resource implications.

Recommendations

1. Data collection

1a. Data collection

All Renal Units should be required to return data to the UK Renal Registry, which collects a comprehensive standardised data set. Individual units need to ensure that their data collection is valid and reliable. While the coverage of the Registry continues to increase, it is still not complete for England. Until data collection is comprehensive, population data reflecting the needs and treatment of geographic populations will be problematic. Population data as currently produced by the UK Renal Registry may still be inaccurate for some parts of the country.

Data for commissioners should be improved. However, improvement is dependant on adequate local data being returned to the UK Renal Registry. The UK Renal Registry should give consideration to producing data by PCT groupings other than former Health Authority boundaries where this is appropriate to the local service.

Commissioners should examine data on uptake of renal replacement therapy and type of renal replacement therapy for their population and ensure uptake is appropriate to need.

1b. Data funding

While the current funding mechanisms for the UK Renal Registry offer a degree of independence, commissioners should explicitly identify funding for the UK Renal Registry in contracts.

Data collection in Renal Units should also be explicitly funded through contracts. Data access in outpatient departments should be reviewed and patient data should be fully accessible in all outpatient departments. Proper data links to the main Renal Unit should be put in place. One key component of

this is the provision of local electronic patient data so that up to date patient data (e.g., blood results) are available. Data links to the main unit and to local pathology results are needed.

At present the UK Renal Registry provides copies of its Annual Reports not only to Renal Units but also to PCTs. This is quite costly and better use of resources might be made by providing PCTs with summary reports only with on-line access to the full report (http://www.renalreg.com/home.htm).

2. Service planning and commissioning

2a. Future prediction of need

Local data are required to enable commissioners to examine potential trends. This will not be resolved in all areas of the country until the UK Renal Registry achieves completes coverage.

2b. Service commissioning group

The existing Regional Commissioning Group in the North East & Cumbria is an essential means of ensuring that appropriate renal services are provided for the populations served by the region's four Renal Units. The Strategic Health Authorities and their PCTs need to ensure that a longer term remit is provided for this group.

Individual Renal Units should be required (through the commissioning process) to audit their performance against the UK Renal Registry data.

2c. Population factors

The consequences of an ageing population and increasing incidence of diabetes need to be adequately considered when planning renal services.

3. Staffing

3a. Staffing levels

Staffing level should be reviewed. Additional clinical staff may be required, but use of innovative approaches, such as nurse practitioners or written referral mechanisms, may be possible solutions.

Sufficient consultant staff should be in place to develop outpatients in areas currently poorly served. Equity in the provision of junior medical staff needs to be considered.

3b. Staff mix

Only one Renal Unit makes use of technicians in haemodialysis. With a shortage of senior nurses it may be appropriate for all units to consider this in the future.

The role of nurse specialists and nurse practitioners should be further developed. The nurse consultant model used in the Durham satellite should be reviewed and developed more widely, where appropriate.

4. Care pathways

4a. Screening in primary care

GPs should incorporate screening for urea, electrolytes and creatinine into their baseline screening protocols for diabetes, ischaemic heart disease and high blood pressure. It is probably appropriate to incorporate this into the annual reviews of these patients, although the scientific basis for this is less clear. Where creatinine is high, urine should be tested for protein in primary care.

4b. Primary care referral guidance

Interview findings suggest that insufficient patients with a high creatinine (over 150 µmol/l) are currently being offered a renal opinion. Some patients may be stable and can be managed in primary care. Options include referral to specialist geriatrician, referral to renal medicine, and use of a diagnostic guideline to determine the need for renal input.

Guidelines for referral from primary care should be developed and implemented. These should cover:

- Types of patients to be referred;
- Level of blood results where referral is needed;
- List of information required.

A review of hospital outpatient services is required to determine how such extra work load would be managed. Options include a more innovative referral system aiming to identify those patients who require outpatient assessment through the use of a protocol, enabling stable patients to be managed in primary care, or using a protocol as the basis for developing a nurse-led service.

The Regional Commissioning Group should work on the development of such a protocol and identify appropriate routes for implementation.

4c. Erythropoietin in primary care

Shared care guidelines for the use of erythropoietin in primary care should be in place in each Renal Unit and surrounding PCTs. It is recommended that a shared care protocol is agreed by the Regional Commissioning Group and then adopted and implemented by each PCT, so that safe and efficient local care may be provided to patients.

4d. Pre-dialysis counselling

All units should offer pre-dialysis counselling. The Sunderland Renal Unit should develop more explicit local counselling.

4e. Vascular access

Surgical links to renal medicine for the provision of vascular access are needed and should be more clearly defined in some Renal Units. More use could be made of clinical specialists in association with vascular surgeons. Much vascular access surgery only requires regional anaesthesia, rather than general anaesthetic. Units should review their surgical links and work on the development of specialist teams.

The surgical unit at Newcastle needs to ensure planned developments to increased staff numbers are implemented. Links to radiology, the level of radiology input, and radiology staff mix should be reviewed in Newcastle.

5. Patient access

5a. Access to renal replacement therapy

The Northumberland area has poor local dialysis provision and the development of a satellite unit planned for Wansbeck General Hospital in Ashington should be a priority. If a further satellite is developed in the south of the region consideration should be given to whether this could be provided in the East Cleveland area.

Newcastle should ensure implementation of plans so that all patients can be offered haemodialysis in day time hours, and only those patients who wish it should be on a shift finishing at 2.00 a.m.

5b. Access to outpatients

The south of the region is well served by local outpatient facilities. The northern part should be provided with more accessible local outpatients. Poorly served areas at present include South Tyneside, North Tyneside, and Northumberland.

Renal Units should review their provision of outpatients through the Regional Commissioning Group, and ensure more accessible provision is put into place.

5c. Transport

There are problems with delays to transport for some Renal Units. Individual Renal Units should review their performance and identify the nature and length of delays and work with patients to examine how to improve the service.

6. Transplantation (Newcastle only)

6a. Donor organs

The non-heartbeating donor programme needs to be further evaluated and developed as appropriate. Increased surgical input with more than one specialised surgeon is essential to maintaining the current services and planned developments.

6b. Time from harvest to transplant

The length of cold ischemic time should be reviewed, and the service provision examined to determine if it is possible to reduce it.

6c. Theatre access

Access to theatre for transplants should be improved. This, however, requires consideration alongside other emergency services.

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